

THE PATIENT-REPORTED IMPACT OF MYOTONIC DYSTROPHY (DM) ON EMPLOYMENT STATUS: DATA ANALYSIS FROM THE ITALIAN NATIONAL REGISTRY FOR DM

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BACKGROUND

The value of employment has been worldwide pointed out to be an important factor for preservation of mental and physical health. This statement is even more relevant in people presenting chronic disabilities, above all in the ones affected by multisystemic diseases, such as Myotonic Dystrophies (DM). Therefore, it is important to recognize that DM can be used as a valuable model to assess the relative impact of the disease on the employment status to further enhance the understanding of this important topic.

METHODS

Data from 328 adult DM patients - 307 DM1 (93.6%) and 21 DM2 (6.4%), mean age 41.84 ± 15.26 yrs - the ones who correctly filled in self-report sheets, consecutively enrolled in the Italian National Registry for DM from February 2013, were analyzed. The information collected about the employment status have been correlated with patients' feeling of being conditioned by DM, gender, educational level, having affected relatives and severity of the disease.

In DM1 group, male are 48.35% while female are 51.65%.

Family history is positive in 48.53% of patients.

13.68% of patients achieved a University degree, 43.32% Upper Secondary Education, 33.23% Lower Secondary Education, 5.54% Primary Education while 5.54% of them are illiterate.

40.72% has an occupation while 21.82% are unemployed, 15.31% pensioners, 12.38% students, 7.82% housewives, 1.95% other.

28.33% refers work life to be affected by the disease

In DM2 group male are 47.36% while female are 52.64%.

Family history is positive in 21.05% of patients.

5.26% of patients achieved a University degree, 42.11% Upper Secondary Education, 36.84% Lower Secondary Education, 15.79% Primary Education while none of them is illiterate.

36.84% has a job while 5.26% are unemployed, 47.37% are pensioners, 5.26% students, 5.26% other.

31.57% refers that the disease had an impact on work life.

RESULTS

In our global DM population 66% of patients have an occupation while 34% are unemployed. There are no significative differences related to sex.

The professional life of 55% of working people is not conditioned by the disease while 45% of them think that DM has an influence on their working life. When asked about the type of influence, most of patients (45.74%) answered that they had to change their work type according to physical limitations, 17.02% said to have a legally protected work status while seemingly only in 1% patients DM conditioned early retirement.

20.21% think that DM conditioned their working life but they didn't specify how it happened.

16% claimed job losses as a result of their medical condition.

The 22% of the employed patients have a Tertiary level education, 49.24% have an Upper secondary education, 28.03% have a Lower secondary education while only 0.8% have a Primary education.

All the illiterate patients are unemployed.

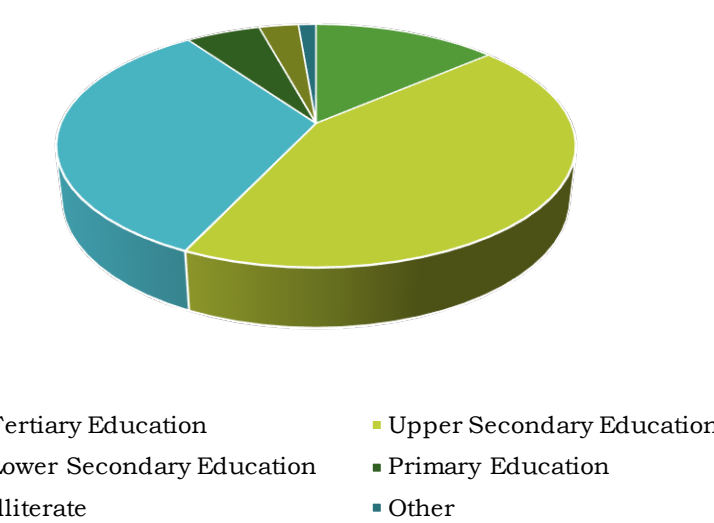
In DM1 group there was no correlation between higher MIRS score and unemployed status, in fact in over 50% of patients who have a job the MIRS score is ranging from 3 (25%) to 4 (30.56%) while in 25% of active workers the MIRS score is 1 and in 19.44% it is 2.

A relationship between MRC and professional life was not observed in DM1 nor in DM2 patients.

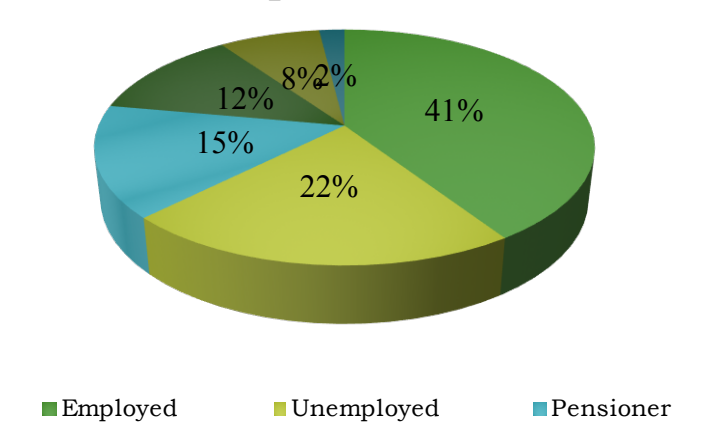
CONCLUSIONS

Information entered by patients in the Italian DM Registry provided a broad overview of the working DM population. A major proportion (about 2/3) of DM patients are employed and less than half of these ones (45%) think that to be affected by the disease conditioned their working life. Despite this, some people (16%) feel to have been forced out of work as a result of having DM. Undertaking work revealed statistically significant correlation with a higher level of education as well as higher level of education increased the chance of employment and it reduces the feeling of being biased by DM. Even if DM causes significant disability, it doesn't appear to preclude patients from having a job. Family history of DM doesn't seem to have any connection to the level of education acquired by patients nor to their working life. The correlation between CTG repeat expansion, educational level and employment is ongoing. Between-group analyses revealed significant factors that proved their being related to employment. These results identified previously unrecognized factors influencing the disease and its personal and social implications; therefore, they should be taken into account in the design of future clinical trials.

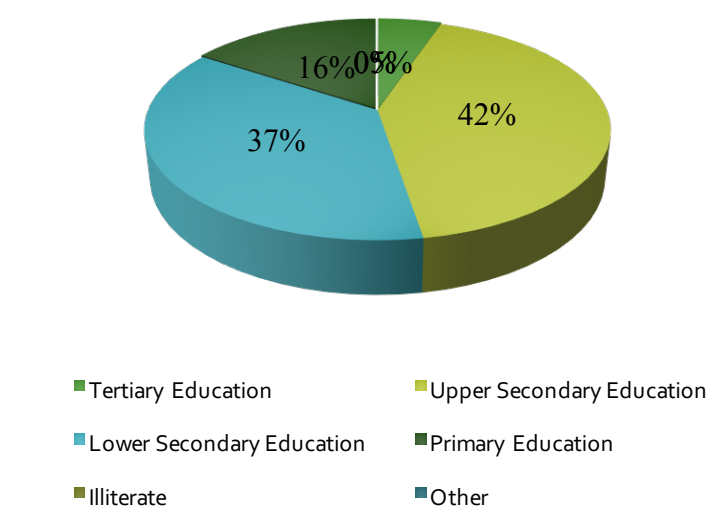
Educational level in DM1 patients



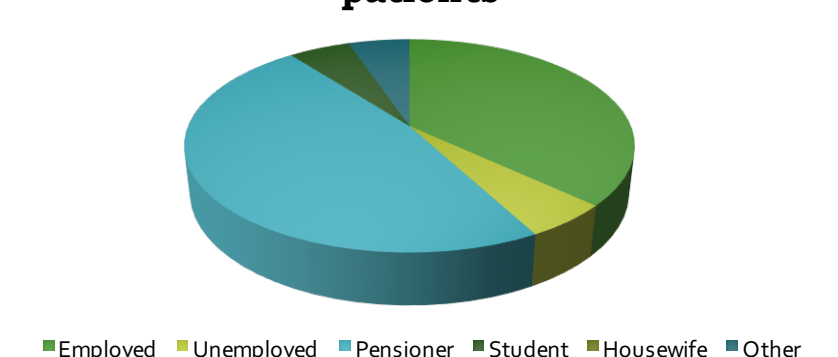
Employment status in DM1 patients



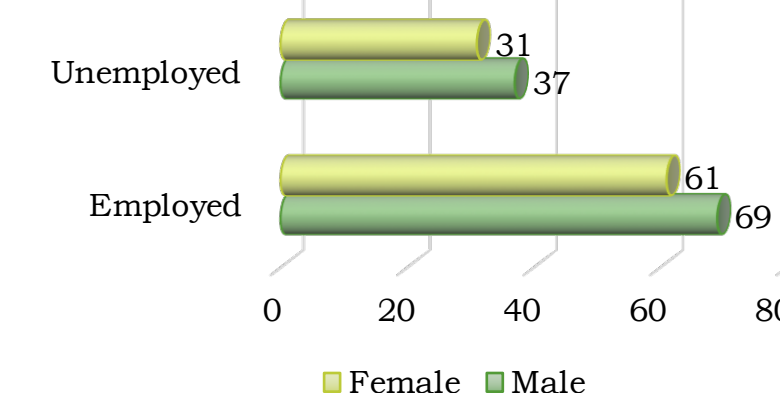
Educational level in DM2 patients



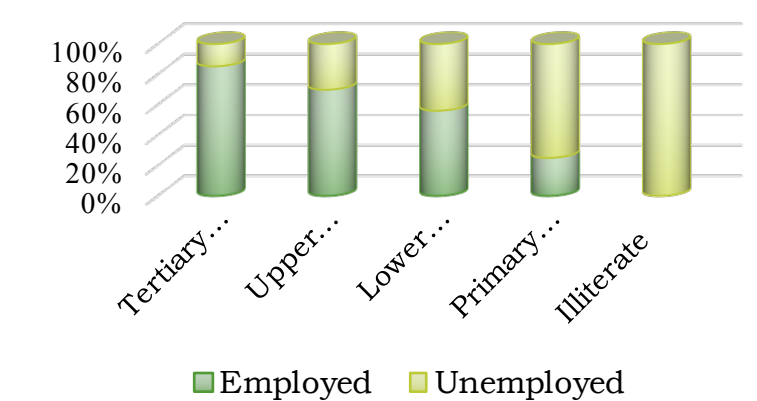
Employment status in DM2 patients



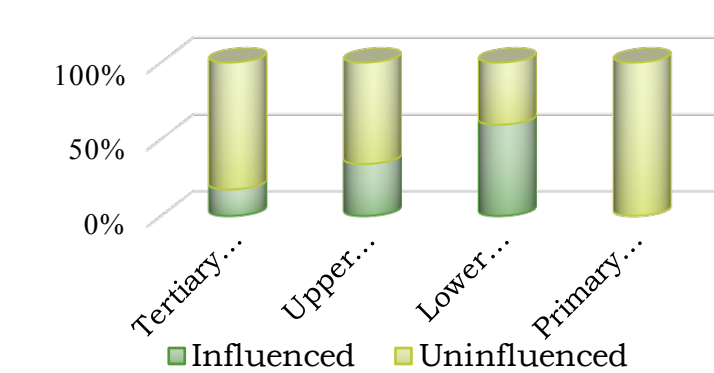
Female Employment vs Male Employment



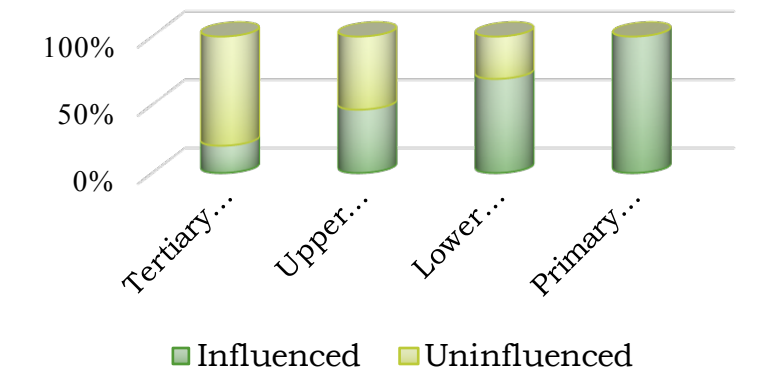
Employed/Unemployed vs Educational level (P-value: 0,0029)



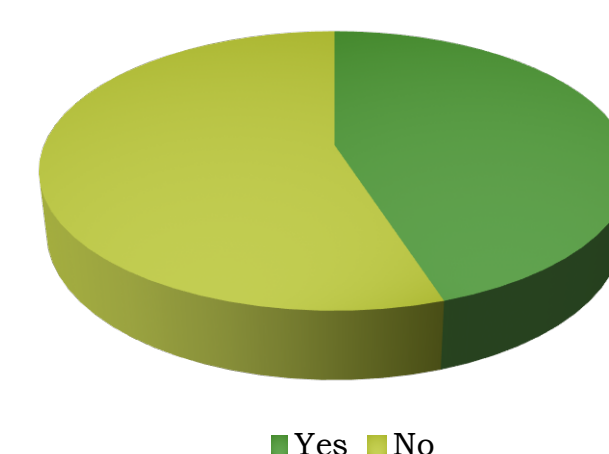
Employed vs Educational Level (P-value: 0,003)



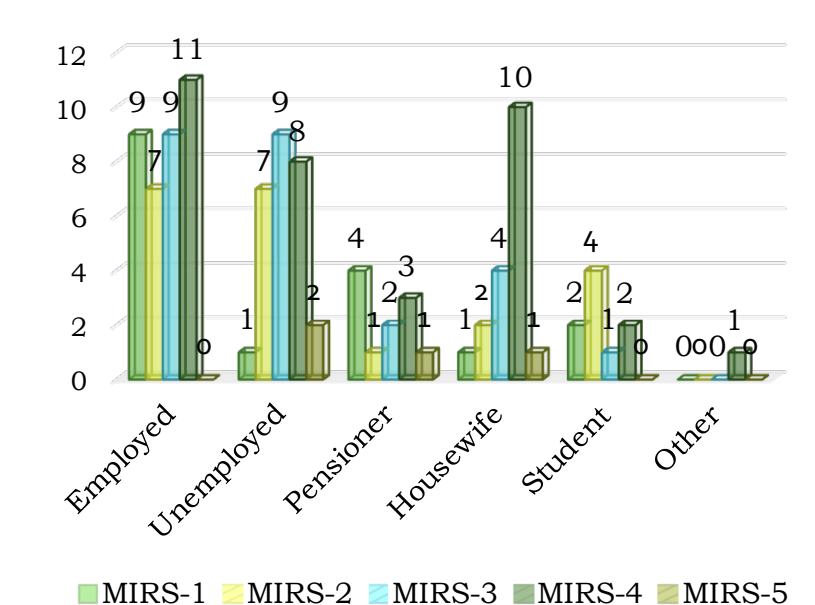
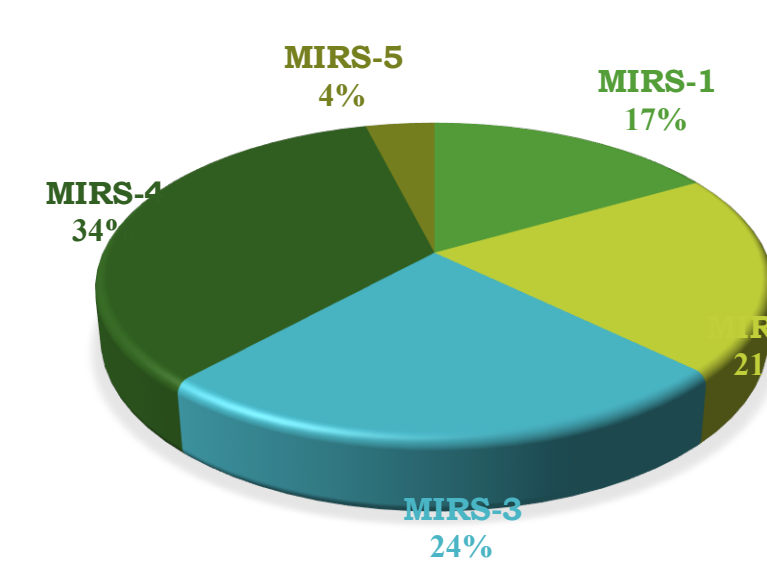
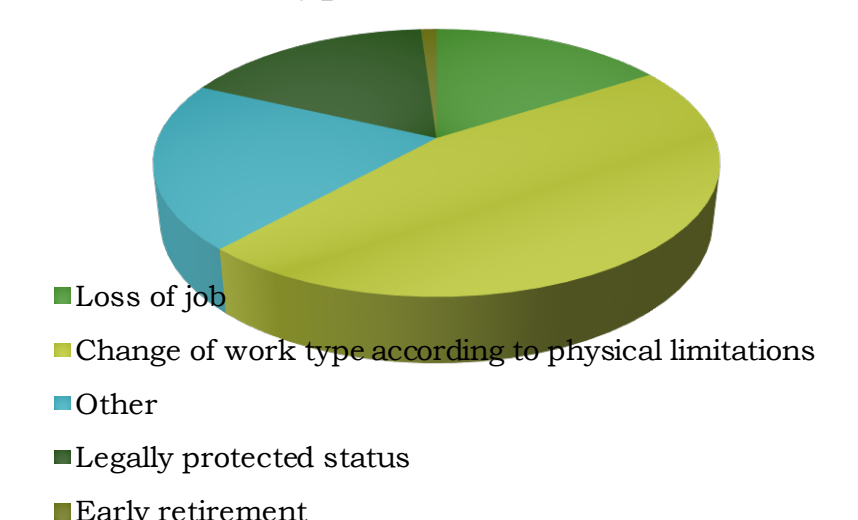
Unemployed vs Educational level (P-value: 0,045)



Perception of being Influenced by the disease



Type of influence



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